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ABSTRACT

In this assessment of federal legislation and programs affecting coordination of services to people with disabilities, actions are addressed which can lead to a more comprehensive and coherent service delivery system. Past coordinative efforts have attempted to resolve problems occurring at both the policy level and in program administration. Current coordination efforts include several interagency entities such as the Architectural and Transportation Barriers Compliance Board, the Interagency Committee on Handicapped Employees, the Administration on Developmental Disabilities, and the Interagency Coordinating Council mandated by the Rehabilitation Act of 1973 (as later amended). The National Council on the Handicapped considers coordination activities as one of its major responsibilities, and intends to use its unique position as an advisor to both Congress and the executive branch of the government to facilitate the implementation of a coordinated disability policy at the national level. A recommendation is proposed requiring state and local agencies that receive federal funds for services for people with disabilities to participate in the development of coordinated service delivery plans. (JDD)

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TOPIC PAPER J:

COORDINATION

National Council on the Handicapped

February, 1986

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I. INTRODUCTION

Our Federal system of government is based on laws legislated by Congress and administered by the Federal agencies. To a large extent, the administration of Federal programs mirrors the separations established by the Congressional committee system--each committee (and each agency) is responsible for relatively discrete, functional areas. Coordination problems arise because legislation in one area can have such tremendous effects on other areas. For instance, transportation legislation ultimately affects, among other things, food distribution, interstate commerce, and the ability of disabled people to get from one place to another.

The Federal organization is replicated to a certain extent at the State and local levels. State legislatures and local governing boards also determine policy through legislation, which State governors and local mayors implement. This system creates our "layer cake" system of government. Over the years the layers have become intermingled or "marbelized," as the Federal government has moved into more and more areas that formerly were exclusively the domain of the States. Because of the many interrelationships among the Federal, State and local levels of government, State and local bureaucracies are often organized around the same general functional areas as our national government.

Given this functional organization of our government, it is natural that legislation, and the programs that implement that legislation, are scattered throughout Congress and the Federal government. It is also natural that gaps and duplications occur over time as Congress and the Administration attempt to meet the diverse requests of varied and vocal constituency groups. As a result, it is extremely difficult for any public or private organization to provide the kind of effective coordination that theory might dictate. In reality, effective coordination usually results from a combination of legislative measures, collegial

interaction and skillful persuasion. By its actions, Congress has certainly approved the efficacy of the collegial model.

In this report, the Council avoids unrealistic assumptions about the ability of any organization to coordinate services in the abstract sense. The Council does address actions which can lead to a more comprehensive and coherent service delivery system.

This country's disabled citizens are a particularly vulnerable population with a wide range of diverse needs. For this reason, they often need a broader range of services, and encounter greater problems when they encounter disjointed and fragmented services, than do other citizens. Although some inefficiences will always occur in our service delivery system, the Council finds that coordination problems are creating major difficulties for persons with disabilities. Changes are needed that will reduce costs and improve the ability of the system to support the independent living and self-sufficiency goals established in the nation's policy on disability.

II. THE COORDINATION PROBLEM

Coordination is a complex issue that is not subject to simple approaches and solutions. The complexity occurs both at the policy level and in program administration.

A. Policy Development

Policy development is not a clear cut process. It occurs at many levels and in many ways throughout the system. When Congress creates policy by developing legislation, it draws on many sources: assessments of need and program effectiveness, political and fiscal considerations, information about state-of-the art remedies to perceived problems, and the past experiences of the legislators themselves and of the people they consult for information.

Congress often creates programs that are implemented by the Administration. The policy that guides those programs is of course the authorizing legislation, supported by the committee reports that were prepared in the process. Administrative staff use these materials to develop regulations, which become operating program guidelines. Together, the legislation and regulations provide the legal basis for the program. Although proposed legislation normally goes through the committee hearing process which provides an opportunity for wide review and comment by concerned citizens and organizations, the programs that result from this process essentially reflect the functional, separate-track orientation of the development process.

Congress has made a major effort to coordinate its own efforts on behalf of people with disabilities by establishing two subcommittees that specialize in disability issues: the Subcommittee on Select Education in the House of Representatives and the Subcommittee on the Handicapped in the Senate. These committees are supportive of the Council's efforts, and committee staff members

make every effort to track and coordinate legislation that affect disabled people. The President and his Cabinet, through their administrative authority, are also actively involved in policy development. They have access to much of the available information about the need for programs and services and the effectiveness of current programs; the way that information is analyzed and presented greatly affects policy development. In addition, program implementation is greatly affected by the amount and quality of attention it receives from top administrators; benign neglect can stifle a program no matter what the official policy. The timing and quality of appointments and the budget control exercised by the Office of Management and Budget are also effective policy tools at the President's disposal.

The White House has demonstrated a strong interest and commitment to the Council's efforts to improve the policies that govern the delivery of services to people with disabilities. For example, in July the White House hosted a luncheon for representatives of the National Council on the Handicapped, the President's Committee on Employment of the Handicapped, the President's Committee on Mental Retardation, and the Architectural and Transportation Barriers Compliance Board. This reportedly was the first official White House briefing ever conducted for Presidential appointees who work on disability issues.

B. Program Administration

Each agency implements its programs by following the guidelines outlined in its regulations. The nature of the regulation-development process, with its stringent adherence to authorizing legislation, means there may be little regard for the impact of one program on another. Each program has its own set of objectives, priorities, and eligibility conditions. Although proposed regulations always go through a comprehensive review process, other program offices may not

have the staff resources to adequately review proposed regulations to determine their impact in other areas--we are talking about thousands of pages of regulations.

Coordination efforts are further complicated because programs are managed at different levels in the system. For example, SSDI and Medicare are managed at the national level; SSI, Medicaid and vocational rehabilitation are administered at the State level; and most housing and transportation programs are managed locally.

Since the 1960s, private nonprofit organizations have become increasingly involved in providing services to disabled persons. These services, many of which are funded by Federal grants and private donations, further complicate the service delivery picture since these programs, too, operate according to their own guidelines and priorities. When we talk about the many Federal programs that serve disabled people, it is important to realize that relatively few are targeted specifically at disabled people; the rest serve the general population, which includes disabled people. This is as it should be--in general, disabled people need many of the same or similar services as their able-bodied peers.

Problems result because each agency, following its own regulations and procedures, independently makes decisions about recipients or beneficiaries. For instance, in at least one State some disabled persons nave been denied SSDI benefits, on the grounds that their disabilities were not sufficiently severe, and were also denied Vocational Rehabilitation services because their prognosis for employment was too poor. The problem arises because the Social Security Administration and each State vocational rehabilitation agency uses separate eligibilty criteria. Each program was designed to achieve quite different goals. One provides income support only to individuals who are deemed unable to work because of their disability; the other provides services only to individuals who

show promise of being able to work after receiving services. The programs and coordinative mechanisms expected to resolve such problems vary considerably from State to State.

Reports from the White House Conference on Handicapped Individuals in 1977 and from the Forums held by the Council in 1984 and 1985 amply document the extent and severity of these problems. In addition, disabled people repeatedly cite the difficulty of finding information and services: too often they are sent from one place to another in search of services.

III. PAST COORDINATIVE EFFORTS

Over the years both Congress and the Administration have responded to the coordination issue. For instance, in 1978 Arabella Martinez, then Assistant Secretary for Human Development, proposed an administrative reorganization within the Department of Health, Education and Welfare that pulled together the Rehabilita- tion Services Administration, the Developmental Disabilities Office, the President's Committee on Mental Retardation, the Office for Handicapped Individuals, and the Architectural and Transporta- tion Barriers Compliance Board. The new Administration for Handicapped Individuals died aborning when the Rehabilitation Services Administration and Special Education were moved to the Department of Education.

The original mission of the Office of Handicapped Individuals (OHI), which was created by the Rehabilitation Act of 1973, was to coordinate programs for disabled people. It failed because it was unable to rapidly accummulate knowledge about Federal programs, and lacked the staff resources needed to pinpoint coordination needs and to effectively advocate for disabled people before other agencies. The Information Clearinghouse on the Handicapped, which was lodged in OHI, was moved after the demise of OHI to the Office of Special Education and Rehabilitative Services. The Clearing- house is now also defunct; some of its functions are being conducted under contract.

An Administration on Disabilities has been proposed repeatedly over the years as a solution to the coordination problems in the disability field. Although past attempts in the disability field have failed, an approach which may work is in place: the Older Americans Act created an Administration on Aging that provides a focal point for issues of concern to elderly persons. The implementation of the Act has resulted in increased interest, programs and funding in the aging field. The Administration on Aging has a unique network of 57 State and some 700 area

agencies that provide statewide planning and social services at the local level, including multi-purpose senior centers with information and referral services. Some of these area agencies are very effective conduits for local public and private sector networking and community action activities. In fact, the strength of the Older American's Act is grounded in the services and activities of the area agencies on aging.

Although it was not primarily a coordinative effort, the White House Conference on Handicapped Individuals was a major, national policy development effort that obtained information on policy issues from disabled consumers all over the country. The Conference gave rise to governor's and mayor's committees that guided and coordinated local efforts; some of these committees survive today.

As a direct result of the White House Conference recommendations, an advisory position was created in the White House. The influence and impact of the position, which is now held by a Senior Staff Member in the Office of Policy Development in the Executive Office of the President, depends on the political expertise and ability of the incumbent. The Conference also gave rise to the National Council on the Handicapped, which is discussed in the following section.

IV. CURRENT COORDINATIVE EFFORTS

A number of interagency entities address specific aspects of services to disabled people. Brief descriptions of several of these entities follow.

- The Architectural and Transportation Barriers Compliance Board is an independent board composed of heads of a number of Federal agencies and departments. Its activities are regulatory in nature and are limited to architectural and transportation accessibility compliance issues.
- A Federal Agency Council advises the Census Bureau on census topics and issues.
- The Interagency Committee on Handicapped Employees is mandated by Section 501 of the Rehabilitation Act of 1973. This committee addresses employment issues within the Federal Government.
- A Disability Advisory Committee has been proposed to provide advice on disability issues within the Social Security Administration.
- The Interagency Committee on Handicapped Research is chaired by the Director of NIHR. Its membership includes agency heads designated by the President. The Committee has a mandate to identify, assess, and seek to coordinate all Federal program activities related to rehabilitation research.
- The President's Committee on Employment of the Handicapped emphasizes public outreach to increase employment of disabled people.
- The President's Committee on Mental Retardation was created during the 1960's in response to the Kennedy Administration's recognition of the need to develop services for mentally retarded individuals.
- The Administration on Developmental Disabilities was established by the Developmental Disabilities Assistance and Bill of Rights Act of 1963. The Administration provides a national planning focus for programs that serve individuals with developmental disabilities.

In addition, Congress mandated an Interagency Coordinating Council in the Rehabilitation Act of 1973 (amended February 22, 1984, PL 98-221), under Section 507. It is composed of the Secretary of Education, the Secretary of Health and Human Services, the Secretary of Labor, the Attorney General, the Chairperson of the Office of Personnel Management, the Chairperson of the Equal Employment Opportunity Commission, and the Chairperson of the Architectural and

Transportation Barriers Compliance Board. Executive Order 12250 names the Attorney General as chairperson, a function which he has delegated to the Assistant Attorney General for Civil Rights. The Council is to develop and implement:

> ...agreements, policies, and practices designed to maximize effort, promote efficiency, and eliminate conflict, competition, duplication, and inconsistencies among the operations, functions and jurisdictions of the various departments, agencies, and branches of the Federal Government responsible for the implementation and enforcement of the provisions of this Title and the regulations prescribed thereunder.

The Council's report on its activities is to be filed annually on July 1. Thus far the Council has met six to eight times per year to address issues related to Title V. The Council does not now include the National Council on the Handicapped.

V. NATIONAL COUNCIL ON THE HANDICAPPED

Congress created an independent National Council on the Handicapped (NCH) to provide advice on disability policy to the Administration and Congress. In addition to its responsibilities to advise the Commissioner of the Rehabilitation Services Administration on policies and programs, and to provide policy direction to the National Institute of Handicapped Research, Congress required NCH to:

> (4) Review and evaluate on a continuing basis all policies, programs, and activities concerning handicapped individuals and persons with developmental disabilities conducted or assisted by Federal departments and agencies, including programs established or assisted under this Act or under the Developmental Disabilities Assistance and Bill of Rights Act, in order to assess the effectiveness of such policies, programs and activities in meeting the needs of handicapped individuals (Sec. 401 (a), P.L. 98-221).

Congress reinforced the breadth of this mandate by requesting that the Council:

> (7) Provide to the Congress on a continuing basis advice, recommendations, and any additional information which the Council or the Congress deems appropriate (Sec. 401 (a), P.L. 98-221).

Coordination issues are certainly one of the Council's major responsibilities under this broad mandate. For instance, the Council is recommending in its February, 1986 Special Report to the President and Congress that a Comprehensive Equal Opportunity Law be enacted. Such legislation represents a major step toward providing equal opportunity for disabled people. Enactment of this legislation would establish an important precedent and would directly affect the provision of employment, transportation, and housing services to disabled people.

The National Council on the Handicapped has a mandate which places it in a particularly advantageous position to work on a collegial basis with other Federal agencies. It is in a position to use its persuasive powers to identify gaps and overlaps within the service delivery system, and to advise Congress and the Commissioner of the Rehabilitation Services Administration on specific measures by

which services to disabled people can be improved. As part of its duties, the Council establishes general policies for and reviews the operations of the National Institute of Handicapped Research. In line with that responsibility, the Council plans to use its ex-officio membership on the Interagency Committee on Handicapped Research to support Federal Government agency research on coordinative issues. The Committee's tentative plan to convene consumers and Federal, State and local agency representatives to participate in state-of-the art seminars and conferences on coordinative issues is strongly supported by the Council.

The Council also intends to increase its interaction with private sector organizations concerned with disability. We will continue to emphasize and strengthen our consultations with other public agencies and committees working on disability topics. In addition, the Council will redouble its efforts to inform Congressional staff members about the status of and need for improvements in Federal programs serving disabled people. The Council will monitor and report annually to Congress on this nation's progress on the agenda laid out in the Council's Disability Policy Statement and on the recommendations set forth in its Special 1986 Report to the President and Congress.

In conclusion, the Council intends to use its unique position as an advisor to both Congress and the Administration to increase the sharing of information and to help build better and stronger linkages among relevant policy makers and the programs that serve disabled people.

VI. RECOMMENDATIONS

"Coordinated services" describes the ideal results of a wide range of interactions among persons active in policy and program development. Although these interactions take place every day, their purpose, frequency and quality varies greatly from community to community, from State to State, and from program to program. In the Forums conducted in 1984 and 1985 as part of the Council's preparation for its Special Report to the President and Congress, disabled people around the country declared that many programs do not mesh well with other available services, and that too often the service delivery system exhibits gaps, inconsistencies and inequities. However, there is no single or simple solution to the need for better coordinated services. Therefore, the Council believes that mechanisms should be in place throughout the service delivery system that consistently and purposefully attempt to improve the linkages among the policy makers and programs that serve disabled people.

After a careful study and review of the current service delivery structure, we have determined that the Council itself has a unique mandate from the Congress to facilitate the implementation of a coordinated disability policy at the national level. The Council's disability policy statement, which has been approved by the President, and the assessment and recommendations in the Council's Special Report to the President and Congress, represent major steps in this direction.

The Council appreciates the importance of frequent and purposeful interaction at the national level with all parties involved in policy decisions that affect services to people with disabilities. To that end, the Council pledges to maintain its information base with consumer organizations around the country while strengthening our interaction on coordination issues with State, local and national policy makers, private organizations, the Congress, and the

Administration. This process will continually identify coordinative issues which can best be resolved through specific legislative or administrative action. In addition to these national level activities, State and local planning by recipients of Federal funding should take place in every community. To reinforce the importance of such coordinated planning, the Council makes the following legislative recommendation:

1. Congress Should Require State and Local Agencies that Receive Federal Funds for Services for People with Disabilities to Participate in the Development of Coordinated Service Delivery Plans.

A State planning requirement is in place for citizens with developmental disabilities. The Council recommends that the planning process should address the needs of all citizens with disabilities and that it should be extended to the local level as well as the State level. The planning process should seek the involvement and participation of existing planning mechanisms in each State and community. For this reason, lead agency responsibility and a detailed schedule for the creation of such plans should be assigned by the appropriate governor or mayor.

At a minimum, State and local agencies that receive or administer Federal funds for the following benefits and services should participate in the planning process: Veterans benefits and services; Social Security disability income, health services, long term care and medical insurance programs; education; rehabilitation and independent living services; Title XX; Worker's Compensation; employment and training (Job Training and Partnership Act); housing and transportation; developmental disabilities planning and services. In addition, the process should, by requirement and design, substantively involve people with disabilities in the planning process. The planning process should specifically address methods of improving service delivery. Particular attention should be paid to the needs of individuals with disabilities who do not fit neatly into established service

categories. For instance, careful planning should prevent persons with disabilities who are declared ineligible for SSDI from being denied vocational rehabilitation services. It should assure that appropriate services are delivered to people with multiple handicaps, such as the estimated 15-20% of mentally retarded individuals who also have emotional problems. In States and local communities, the planning process should lead to improved communications, more integrated services and better informed policy discussions. No additional Federal costs are associated with this recommendation; if implemented in good faith at the State and local levels, the planning process should lead to improved services at equal or reduced costs.